

Consent Policy Design Group

Meeting #5

June 4, 2019



Agenda

Agenda Item	Time
Welcome & Introductions	1:00 pm
Public Comment	1:02 pm
Summary of Group Member Comments	1:05 pm
Roadmap to Final Consent Recommendations	1:15 pm
Patient and Provider Identity and Care Map Core Function	1:20 pm
Wrap-up and Meeting Adjournment	2:00 pm

Consent Policy Design Group – Workplan

Meeting Focus	Meeting Objectives
✓ Meeting 1 – 4/9/2019 1pm – 2pm Kickoff and orientation	<ul style="list-style-type: none"> • Review and discuss project charter and proposed process for achieving desired outcomes • Orientation on relevant policies and procedures and semantic alignment / shared understanding of key terms
✓ Meeting 2 – 4/23/2019 1pm – 2pm Current consent policies	<ul style="list-style-type: none"> • Establish understanding around current state of consent policies in Connecticut and bordering states • Consider draft language for a HIPAA TPO consent policy for recommendation to Advisory Council
✓ Meeting 3 – 5/7/2019 1pm – 2pm Focus on TPO consent draft	<ul style="list-style-type: none"> • Review proposed process for the development of a consent policy framework, based on HIE use case requirements • Discuss stakeholder engagement and communication needs
✓ Meeting 4 – 5/21/2019 1pm – 2pm Matching use cases to consent model	<ul style="list-style-type: none"> • Review and discuss received input from Advisory Council or other stakeholders • Review use cases where individual consent is required by state or federal law, or areas of ambiguity
Meeting 5 – 6/4/2019 1pm – 2pm Use Case A discussion	<ul style="list-style-type: none"> • Discuss the pros/cons of a statewide consent policy framework vs. HIE Entity consent policy framework to determine scope
Meeting 6 – 6/18/2019 1pm – 2pm Use Case B discussion	<ul style="list-style-type: none"> • Discuss the various ways that consent could be collected and possible roles for organizations in the consent process • Establish high-level understanding of technical architecture for electronic consent management solutions • Discuss workflows that could provide individuals with information and the ability to manage preferences
Meeting 7 – 7/9/2019 1pm – 2pm Review draft consent framework recommendations – structure and process	<ul style="list-style-type: none"> • Review and discuss strawman options • Develop draft recommendations for consent policy framework
Meeting 8 – 7/23/2019 1pm – 2pm Vote on draft recommendations	<ul style="list-style-type: none"> • Finalize and approve recommendations • Discuss stakeholder / general population engagement and communication process

The Consent Policy Design Group

- Stacy Beck, RN, BSN* – Anthem / Clinical Quality Program Director
- Pat Checko, DrPH* – Consumer Advocate
- Carrie Gray, MSIA – UConn Health / HIPAA Security Officer
- Susan Israel, MD – Patient Privacy Advocate / Psychiatrist
- Rob Rioux, MA* – CHCACT / Network Director
- Rachel Rudnick, JD – UConn / AVP, Chief Privacy Officer
- Nic Scibelli, MSW* – Wheeler Clinic / CIO

* Health IT Advisory Council Member

The Support Team

State of Connecticut

Allan Hackney

Health Information Technology Officer
Chair, HIT Advisory Council

CedarBridge Group

Carol Robinson

Michael Matthews, MSPH

Ross Martin, MD, MHA

Chris Robinson

Velatura

Tim Pletcher, DHA, MS

Lisa Moon, PhD, RN

Public Comment

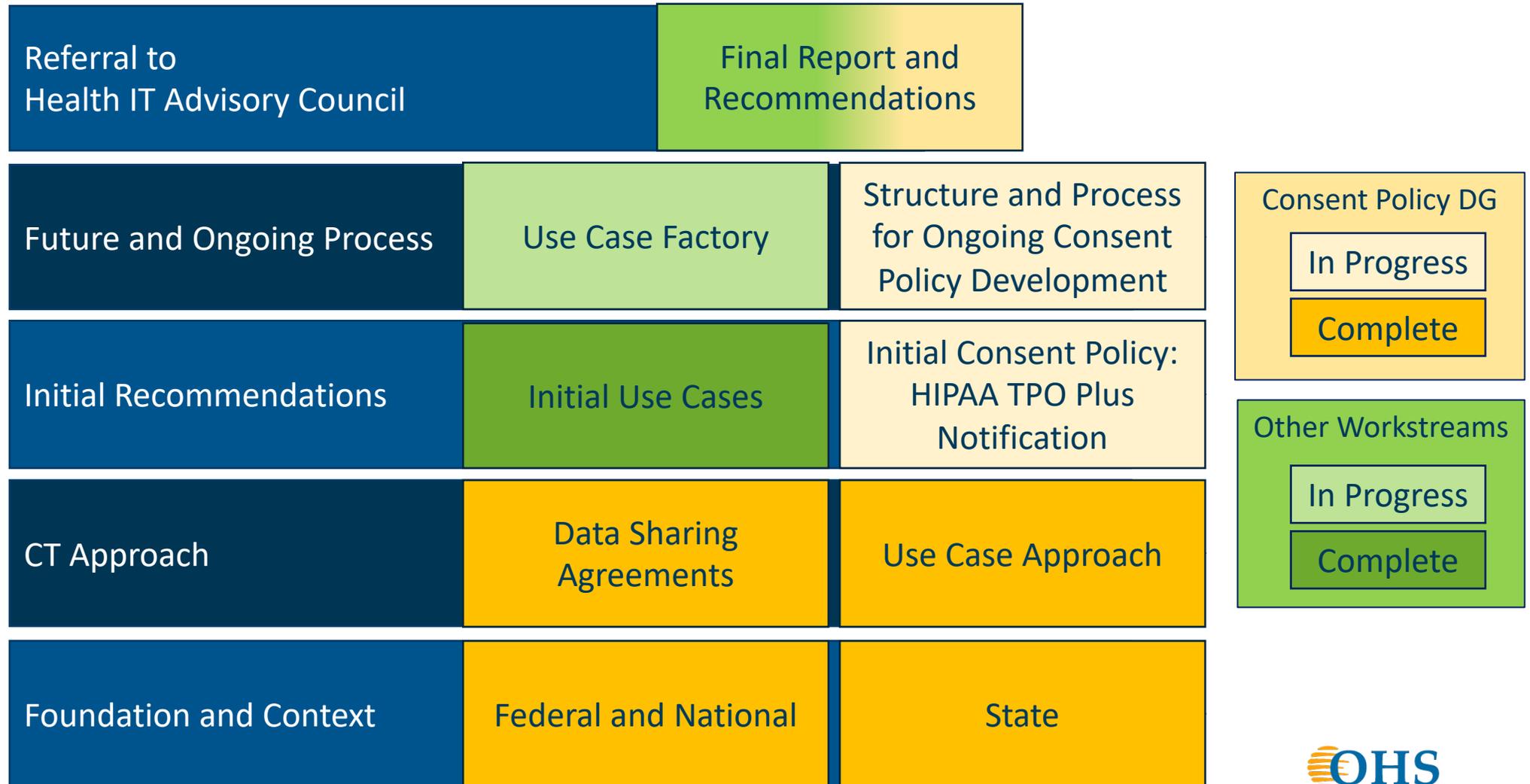
Summary of Group Member Comments

Questions and Comments from Group Members

- It's difficult to do this work in 1-hour blocks of time.
- Exactly what data are being exchanged?
- Exactly what data are being stored?
- Are all data PHI or are some data de-identified?
- Exactly who has access to data?
- Where do notices fit into our discussion and recommendations?
- What data are mandated for reporting to the State and is patient consent required?
- What happens to our recommendations once they are delivered to the Health IT Advisory Council?
- Have national initiatives, like eHealth Exchange, already solved the issues related to consent? Will certain use cases be permitted without patient consent?

Roadmap to Final Consent Policy Recommendations

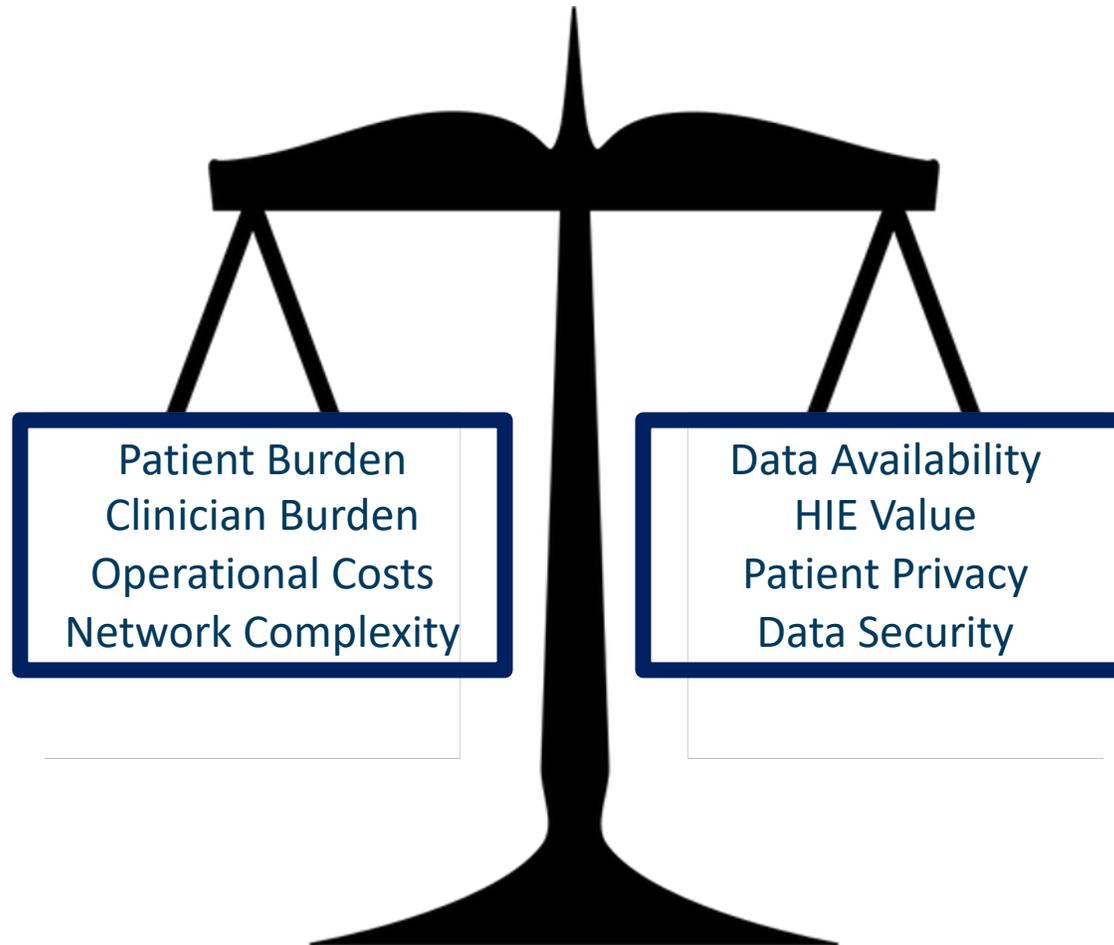
Consent Policy DG Process Review – Where We Are Now



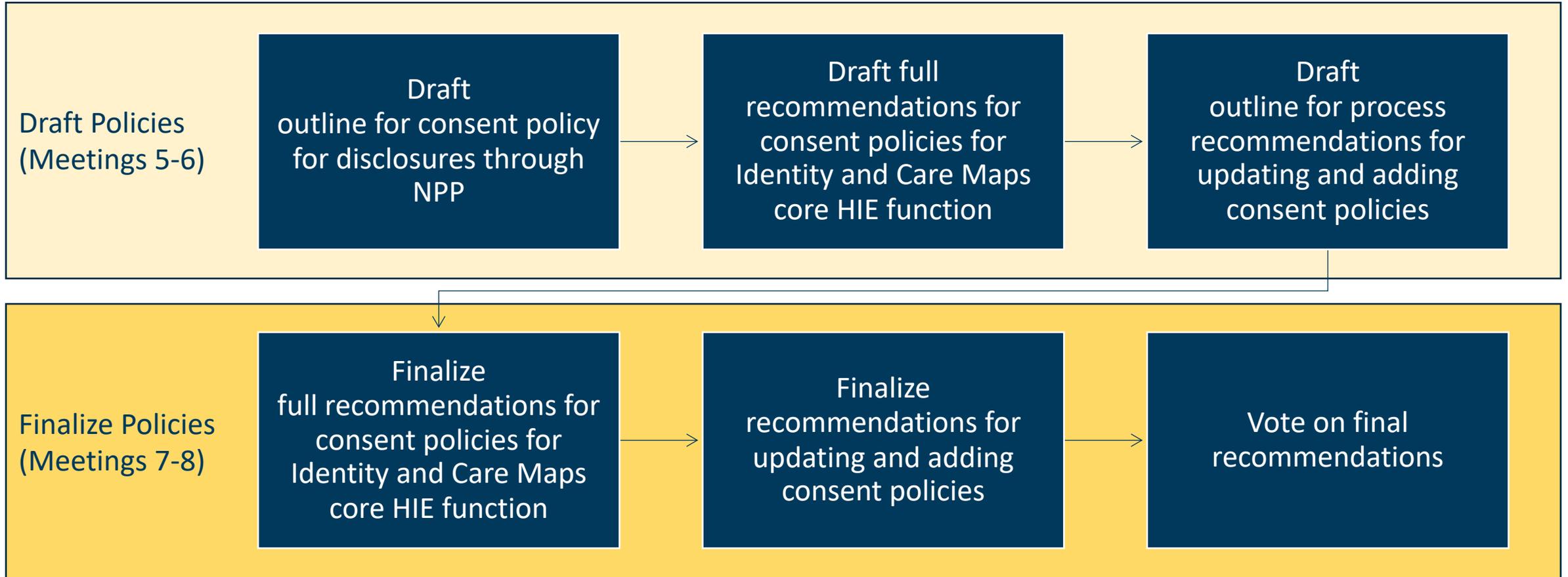
What is out-of-scope for this Design Group?

- **Our work assumes that:**
 - **Security will be managed appropriately.** This includes: user access; data security in motion and at rest; HIE vendor management; User and vendor auditing; application of breach notification policies, etc.
 - **Use Cases have been prioritized through the Use Case Factory process.** Our job is to recommend consent policies for each use case.
 - **Data is accessible only to those who have a reason to access and their use is monitored and audited.**
 - **The work we are doing is the beginning of an ongoing process for addressing consent policy issues.**
 - **The HIE Entity will create detailed implementation methodologies and workflow processes to support the final consent policies.** We don't have to "micromanage" their operations, but provide high-level policy recommendations.

Consent Design Balancing Act



Process Between Now and Meeting 8 (July 25, 2019)



Today's task: Draft outline for consent policy for disclosures through NPP that apply to the Identity and Care Map core function use case.

In between meetings: Staff works on synthesizing comments and refining language as draft consent policy.

Consent Policy Design Group Timing

- Meeting 5:
 - Draft outline for consent policy for disclosures through NPP that apply to the Identity and Care Map core function use case.
 - *In between meetings: Staff works on synthesizing comments and refining language as draft consent policy.*
- Meeting 6:
 - Draft full recommendations for consent policies for Identity and Care Maps core HIE function.
 - Draft outline for process recommendations for updating and adding consent policies.
 - *In between meetings: Staff works on synthesizing comments and refining language as final consent policy for Identity and Care Map core function and drafting process for updating and adding consent policies.*
- Meeting 7:
 - Finalize full recommendations for consent policies for Identity and Care Maps core function.
 - Draft full recommendations for updating and adding consent policies.
 - *In between meetings: Staff works on synthesizing comments and refining language as initial recommended consent policies to prepare for final discussion and vote.*
- Meeting 8:
 - Finalize consent policy recommendations (voting). If necessary, develop minority opinion comments.

Patient and Provider Identity and Care Map Core Function

Draft Consent Policy

Wave 1 Use Cases and Core Functions

Use Case / Core Function	Use Authority	Recommended Consent Policy Block(s)	Rationale
Patient and Provider Identity and Care Map			
eCQM Reporting System			
Immunization Information System (Submit and Query / Retrieve)			
Longitudinal Health Record			
Clinical Encounter Alerts			
Public Health Reporting			
Image Exchange			

The Consent Policy Design Group is only focusing on the consent policy for the core use case of establishing patient and provider identity care maps. As the HIE progresses, the ongoing consent policy function will create new policies to support other use cases, reusing and building on this initial work.

Core Tasks for Today

- Outline content of the consent policy for Notice of Privacy Practices Disclosure related to the Patient and Provider Identity and Care Map core HIE function
- This policy should contain:
 - Name of Consent Policy
 - Purpose of the Consent Policy
 - Use Case(s) to which it applies
 - Responsibilities of the HIE Entity
 - Responsibilities of the Participating Organization
 - Responsibilities of the Patient

HIPAA Organizing Principle for Data Sharing

Covered entities* with relationships in common may share individually identifiable health information

- Covered Entities include providers, health care organizations, health care clearinghouses and health plans
- Data sharing for treatment, payment or health care operations

So how do we know which covered entities have a patients in common?

Identity & Care Maps

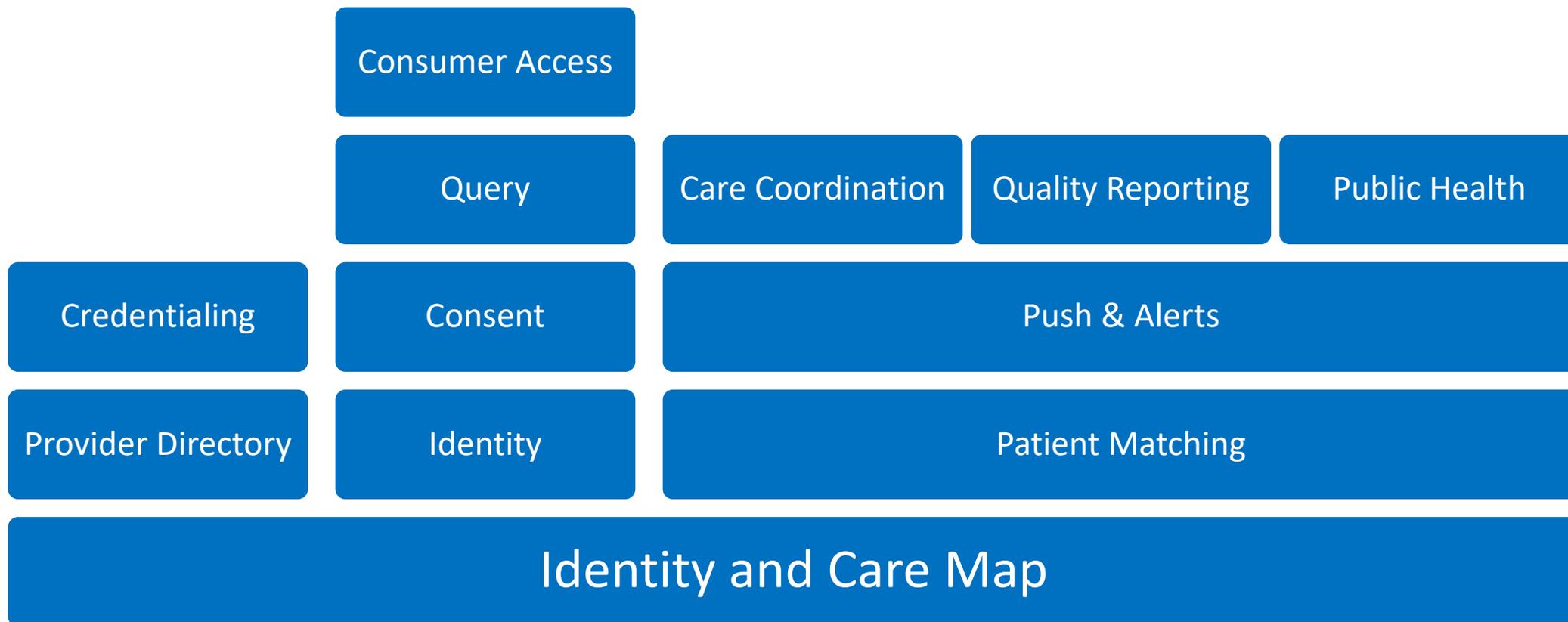
ID&CM identifies the providers actively caring for a patient as well as the payers covering the cost of the patient's care to coordinate all the patient's electronic health information.



What exactly does Identity and Care Maps do?

- Lets providers **declare active care relationships** with patients by submitting patient rosters to HIN
- **Accurately routes information** to alert providers in active care relationships with patients
- **Enables updates to entire care team in real time** with any changes in a patient's status
- **Enables easy views of care team members** by authorized participants

The Foundation for Other Services



Disclosure Notification Policy (example)

- Name: Disclosure Notification
- Purpose:
 - To inform patients and their caregivers and representatives of the existence of the HIE Entity and notify them of the Participating Organization's involvement with the HIE.
 - To give the patient sufficient information on how to seek out additional information on the nature and purpose of health information exchange and allow them to make an informed decision about their participation in the HIE – either through active or passive consent mechanisms or through selecting another provider that does not participate in the HIE.
- Applies to: All approved HIE Use Cases

Disclosure Notification Policy (example)

- Responsibilities of the HIE Entity – Questions for discussion
 - Should the HIE Entity provide content and materials to all HIE participants to support patient notification?
 - Should the HIE Entity provide sample language for inclusion in participants' Notice of Privacy Practices?
 - Should the HIE Entity provide PDFs and print materials at a suitable reading level that provide information for patients about the HIE and its basic services along with links to more on-line patient information?

Disclosure Notification Policy (example)

- Responsibilities of the HIE Entity – Questions for discussion
 - Should there be any recommendations related to language support / translation services
 - Should there be references to relevant regulation, access to consent and participation documents, etc.?
 - Should the HIE Entity publish a continuously updated list of all Participating Organizations and the Use Cases in which they are participating? At what level of granularity?
 - Should the HIE Entity create and maintain a method for patients to sign up to receive regular updates on HIE policies, use cases, and participants?

Disclosure Notification Policy (example)

- Responsibilities of Participating Organizations – Questions for discussion
 - Should the Participating Organizations be required to display information about their participation in the HIE in a patient-accessible location (waiting area, website, etc.)?
 - Should Participating Organizations be required to update their Notice of Privacy Practices (NPPs) and make this available to all incoming patients?
 - Should Participating Organizations be required to distribute updates to NPPs to all active patients on a recurring basis (e.g., annually)?
 - Should Participating Organizations be prohibited from submitting patient information to the HIE until that patient has received notification of their participation in the HIE?
 - Should Participating Organizations be required to provide the patient with an updated account of the Use Cases in which they are participating?
 - Should there be limits on the types of organizations or patient relationships that should be shared under this consent policy?

Disclosure Notification Policy (example)

- Responsibilities of Patients and Caregivers – Questions for discussion
 - Are there any specific expectations for patients and caregivers (e.g., acknowledging receipt of notice of privacy practices related to HIE)?

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Please share comments with the group!

When providing comments:

- CedarBridge will share an outline of the policy recommendations to members and staff within 48 hours of this meeting.
- To make a comment, reply to all and change the subject. Begin all subject headers with [Consent Policy] and the section reference (e.g., [Consent Policy] Responsibilities of HIE Entity).
- Please create a separate email for each section of the policy and include that section header in your subject line.
- If someone has already commented on a section, please add your comments about that section as a response to the initial email. Create a separate email if you want to comment on a different section.
- If you want to make a general comment, please create an appropriate subject header.